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ABSTRACT

There has recently been an explosion of interest and writing about autism, autism spectrum disorders, pervasive developmental disorder (PDD), and pervasive developmental disorder not otherwise specified (PDDNOS). This issue of the "Early Childhood Bulletin" suggests readings for parents, therapists, and professionals serving on Interagency Coordinating Councils (ICCs). Four emerging trends related to autism are discussed, including: (1) increased respect for people with autism; (2) the importance of assessing and treating each child with autism as a unique individual; (3) the effectiveness of using a combination of approaches when working with ch ldren with autism; and (4) the critical need for family involvement in the education of young children with autism. Seven readings of the author's choice are then reviewed, including: "Right from the Start" (Sandra L. Harris and Mary Jane Weiss); "Movement Differences and Diversity in Autism/Mental Retardation" (Anne M. Donnellan and Martha R. Leary); "Little Rain Man" (Karen L. Simmons); "A Parent's Guide to Autism" (Charles A. Hunt); "Resource Guides from the States"; and "Targeting Autism" (Shirley Cohen). The author closes by discussing the impact that the U.S. Departments of Education's early intervention and preschool programs have had on helping young children with autism. (Contains 10 references.) (SG)

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NECTAS

EARLY CHILDHOOD BULLETIN

ONE MOTHER'S REFLECTIONS: RECENT READING ABOUT AUTISM

By

MARTHA ZIEGLER

WINTER

1999

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NECTAS

EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NECTAS

Winter 1999

ONE MOTHER'S REFLECTIONS:
Recent Reading About Autism

by Martha Ziegler, Coordinator, Massachusetts Autism Project
Federation for Children with Special Needs

We are now confronted with an explosion of interest and writing about autism. In one recent one-month period, over 200 people in the Greater Boston region attended each of three different meetings on autism; since all three meetings featured the same keynote speaker, Dr. Barry Prizant, there was probably very little duplication of attendees. Not long ago members of the local chapter of Autism Society of America, sponsor of one of the meetings, were pleased if 50 people came to a meeting.

This issue of ***Early Childhood Bulletin*** has been prepared to assist parents and their professional partners serving on Interagency Coordinating Councils with a useful resource to disseminate to other parents and service providers and to suggest directions for further reading.

Thirty-three years ago, when my daughter was evaluated at the Yale Child Study Center in New Haven, Connecticut, then director of the Center, Dr. Sally Provence, wisely recommended that my husband and I not bother reading any books on autism but instead begin to work with our daughter. I say this was a wise recommendation because she knew that the only book available was Bruno Bettelheim's ***The Empty Fortress***, in which he claimed that autism was caused by cold mothering.

Today's parents and professionals are fortunate to have so many skillful, knowledgeable writers available, among them parents, people with autism, and various professionals. For this article, I reviewed seven books and booklets, dating from one originally published in England in the 1960s to one appearing just a few months ago. Of the hundreds of books now available, I chose books that I believe are especially helpful and interesting for parents of young children with autism, for parents confronted with overwhelming and seemingly urgent decisions. Over the past two years I have read several other recent books, and many more during my daughter's lifetime. Among these additional books, not reviewed here, that I highly recommend are Temple Grandin's ***Thinking in Pictures***, Russell Martin's ***Out of Silence***, and Clara Claiborne Park's ***The Siege***.

While my selections have been personal, made as a parent and as a parent advocate, all the books mentioned here should be of interest to teachers and therapists as well as parents.

(Note: For the sake of brevity, this discussion uses the term "autism" to include "autism spectrum disorder," "pervasive developmental disorder (PDD)," and "pervasive developmental disorder not otherwise specified (PDDNOS).")

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Four Emerging Themes

In reading and reflecting, I found several important themes emerging:

1. Respect for the people with autism themselves has increased greatly. No longer are they seen as having deliberately retreated to some secret, inner world. Nor are they any longer viewed as automatons who must be trained into compliance. They are, instead, seen as significant, individual people who live with a variety of neurological problems that make their lives difficult and complex.

2. Writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored.

"Respect for the people with autism themselves has increased greatly. No longer are they seen as having deliberately retreated to some secret, inner world."

3. Most of the writers whose books I have reviewed for this article agree that what often works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate. Several also advocate inclusion of such additional techniques as sensory integration, speech and language therapy, and facilitated communication for older children still not speaking. All agree that a structured environment is necessary, especially for young children with autism, no matter what types of intervention may be employed, and all emphasize the importance of integration with nondisabled peers as early as possible.

4. Parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly and indirectly.

Recommended Reading

I found that several of the most important books on autism have been regularly updated as new information has been acquired. For example, my copy of ***Children Apart: Children with Autism and Their Families*** by Lorna Wing, has been updated in 1985, 1991 and 1993. In 1974, with Dr. Wing's permission, the Autism Society of America (ASA) revised the book for use by readers in the United States. Wing, who is a parent and also a noted psychiatrist in England, originally published her book in the 1960s. In rereading it, I found that it still is the most important, basic introduction to the subject of autism. Wing and her later editors give a clear description of the syndrome, including the strange history of autism. They clearly and dispassionately present brief descriptions of the various kinds of intervention, concluding that children are served best when various methods are employed. This booklet should be given to every family with a newly diagnosed child with autism.

Right from the Start A helpful discussion of intensive behavioral intervention is contained in a new book (1998), ***Right from the Start: Behavioral Intervention for Young Children with Autism***, by Sandra L. Harris and Mary Jane Weiss. The authors are associated with the Douglass Developmental Disabilities Center at Rutgers University. They make a distinction between "early intensive behavioral intervention" and some of the more common terms like "applied behavior analysis" (ABA). Their terminology discussion is very helpful.

Although Harris and Weiss insist that "applied behavior analysis is essential in the treatment of every child with autism," they do cite several other "exemplary programs" utilizing various approaches: The preschool system in Montgomery County, Maryland public schools; Division TEACCH, University of North Carolina Medical School, Chapel Hill, originators of the teaching methodology now used in many places to teach children with autism; the Walden School, Emory University, Atlanta, Georgia, a toddler-preschool program utilizing a method called "incidental teaching"; and the Princeton Child Development Institute, Princeton, N.J.

In a section called "Common Features of Excellence," Harris and Weiss list the elements that appear again and again in very good early intervention programs: "a rich ratio of adults to children, opportunities for integration with nor-

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mally developing peers, careful planning for the transition from the specialized program to a more normalized program, opportunities for family involvement, and a well developed curriculum" (p. 45). It is interesting to note that these qualities characterize all the effective program models for young children with autism, not just those utilizing an ABA approach.

Right from the Start is reader friendly and a little more open to other ideas than is often the case with writing on ABA and some other approaches that have enthusiastic supporters. The writers have achieved this style while still presenting a strong, clear case for their approach.

Movement Differences and Diversity in Autism/Mental Retardation by Anne M. Donnellan and Martha R. Leary, revised in 1997, is a helpful introduction to the theory of autism as essentially a movement disorder, a concept gaining wider acceptance. Donnellan and Leary, Philip Teitelbaum, Ralph Maurer, and others who write about movement disorder, are not talking about a motor problem, that is, difficulty walking or running; rather, they are describing a neurological barrier that makes it difficult for people with autism to initiate movement, especially production of language, to make transitions from one activity to another, and sometimes to stop or sustain an activity.

This, too, is a reader-friendly, accessible presentation of a complex idea, one that has enormous implications for the way parents and others view people with autism. It is a theory that views them as people with much more competence than earlier theories ascribed to people with autism. Furthermore, Donnellan and Leary have the refreshing habit of admitting earlier mistakes in their own thinking. Donnellan and Leary acknowledge the effectiveness of the discrete trial format as a teaching strategy, but they also urge some cautions, emphasizing the importance of considering the point of view and the needs of the individual child being taught. Because learning with this technique is such hard work, they insist that the behavioral goal be something important for the child, not something trivial or irrelevant, and they offer some useful hints in the application of this method.

Little Rain Man When I picked up ***Little Rain Man***, by Karen L. Simmons (1997), I assumed it was a book for children, but that is not the only, or even primary, audience. Written from the point of view of Simmons' young son Jonathan, it is a projection of what Simmons believes her son thinks and feels. It is an interesting example of one knowledgeable and creative mother's effort to help her son's siblings, teachers, and others understand him.

A Parent's Guide to Autism Charles A. Hart's ***A Parent's Guide to Autism***, published in 1993, continues to serve as one of the basic handbooks for parents, alongside Lorna Wing's ***Children Apart***. Hart has lived with autism both as a brother and then as a father. The 16 chapters of his book pose a series of 16 questions on the minds of almost every parent dealing with autism. Hart begins his chapter on education with the following crucial reminder: "Make sure the school sees your child as an individual, not just as a label or disability. If the word autism becomes the focus, instead of the person, the student and his or her potential could be lost behind the label" (p. 186).

"Writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored."

Hart has a talent for posing some of the most difficult questions and then answering them in a straightforward, commonsense manner. For example, in discussing the causes of autism he agrees with all other current observers that there is a neurological basis for the disability, but he carefully and clearly explains that it comes from a structural rather than a chemical problem in the brain. (Not all researchers agree with Hart on this point, however.) He further emphasizes the fact that there is no cure for autism, no miracles, no magic drugs, but effective education often achieves what looks like miraculous improvement and habilitation. In answering the question, "Why are there so many approaches to education?" he replies that this situation is a result of everchanging theories about the cause of autism. He further points out "Almost any serious

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attempt at education will help some of the students some of the time. For this reason, many of the earliest theories of education still have believers. However, careful evaluation at Division TEACCH and other research centers is making a difference. Education is becoming more of a science and less of a guessing game" (p. 193).

Recent Resource Guides from the States

Several states, including Massachusetts, have recently published their own excellent resource guides and handbooks on autism/PDD. One effective, readable document is the one published for Pennsylvania called, "What We are Learning About Autism/Pervasive Developmental Disorder: Evolving Dialogues and Approaches to Promoting Development and Adaptation." (1997) This is a well-written, well organized primer for helping parents and practitioners with decision making.

"Most of the writers whose books I have reviewed for this article agree that what often works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate."

The Pennsylvania booklet contains brief but clear summaries of the various components in the assessment of autism/PDD: Communication, sensory and movement regulation, learning differences, age and developmental sequence, possible concurrent psychiatric disorders and medical conditions, interests and capacities, friendships and relationships, and social context. Several descriptions are illustrated with real life stories from parents or teachers.

This handbook also contains a comprehensive chapter on the various methodologies and treatments now being offered. There is a brief discussion of such therapies as medication, auditory training, visual training, use of Irlen lenses (colored filters that have helped some children with autism with their visual processing), and biochemical readjustment through supplements and diet. The authors conclude this section with the following statement: "While some medical approaches may be intriguing to investigate, they are no substitute for the lifelong benefits of an appropriate education. Therefore, the following discussion will offer an outline of the *education, accommodation and support strategies* utilized by current teaching methodologies: Applied Behavior Analysis, Developmental or Relationship-based Approaches, Incidental/Naturalistic Teaching, Language and Communication Strategies, Movement Differences and Accommodations, Sensory Integration/Sensory Regulation, Social Skills Training, and Structured Teaching" (pp. 33-34). Each of these methodologies is discussed at some length.

The section on applied behavioral analysis (ABA) is especially helpful because it clarifies often misused terminology, including behavior modification, discrete trial training, and other behavioral techniques.

Several of the handbooks and resource guides published by state agencies have been the outgrowth of state level autism task forces or committees that emerged from the two conferences on autism sponsored by the National Early Childhood Technical Assistance Sytem (NECTAS) held in 1997. Similarly, NECTAS is following up with the preparation of a Policy Options and Considerations paper and a monograph on effective practices that are now being developed with the input of key stakeholders throughout the country. This publication will be widely disseminated to early intervention and preschool practitioners and parents.

Targeting Autism Finally, for a truly comprehensive review of current thinking about autism, I strongly recommend Shirley Cohen's ***Targeting Autism***, just published by the University of California Press. Professor of Special Education at Hunter College of the City University of New York, Cohen has been involved in the education of children with autism intermittently for 30 years. In this book, she reviews the latest research findings around possible causes of the disorder (Bristol, Denckla, Bauman, Teitelbaum, and others) and she reviews the history and current status of the leading teaching approaches: Lovaas, TEACCH, Greenspan's developmental approach, the Picture Exchange Communication System (PECS), the Koegel approach, and others.

Cohen has an interesting, respectful chapter on

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what she terms "alternative treatments": megavitamin and other chemical therapies; auditory integration training; sensory integration therapy; and facilitated communication. She reports the fascinating observation made by Martha Denckla, research neurologist at Johns Hopkins University, that "alternative treatments like auditory integration and sensory integration are closer to the cause of autism than are behavioral approaches" (p. 142). That observation, however, in no way implies that any therapy is more important than good education.

Throughout the book Cohen relies on reports from several adults with autism who have the ability to report on their personal experience. She raises and examines several controversial issues, including those around the newer labels and around the concept of "recovery." She deals at some length with the question of equity; she is disturbed by the fact that generally speaking, only wealthy parents are having access to the intensive, lengthy intervention that is needed when the children are first diagnosed.

I was struck by Cohen's observations in the following paragraph, which confirm what I was seeing as I reviewed the other books:

"A funny thing seems to be happening out there in the world of educational/therapeutic treatment of autistic children. Common elements are appearing in approaches that were considered very different, even antagonistic, as programs learn and borrow from each other. People seem more willing to acknowledge that maybe they haven't had all the right answers. The director of a school that describes its goal as recovery and its approach as applied behavioral analysis told me: 'Maybe it's time to think of a TEACCH model for some children who show few signs of movement toward recovery after a year or two.' The more gentle and loving hand long espoused by programs based on a developmental approach seems to be creeping into programs derived from the Lovaas framework; and the principal theorist of developmental intervention, Stanley Greenspan, is talking about combining behavioral and developmental approaches to better fit the needs of some children" (p. 117).

This is an exciting, although challenging time to be working with young children with autism. We seem to be on the threshold of major scientific discoveries that surely will lead to prevention, or possibly even cure, of the disorder in all its varied manifestations. At the same time, now, parents, state coordinators of early intervention and preschool programs, and state interagency coordinating councils face the immense challenge of finding ways to provide and fund the intensive programs that are needed for the two years or so following diagnosis of the autism spectrum disorder.

"Parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly and indirectly."

Personally, as a parent and advocate I believe that the U.S. Department of Education's early intervention and preschool programs, including demonstration and outreach projects, along with National Institutes of Health research initiatives, have helped push forward earlier diagnosis and development of more effective treatment and teaching methods for our young children with autism. NECTAS, with its core of knowledgeable parents and leading educators and researchers, plays a crucial role as catalyst for this progress.

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Resources

To order materials and request additional information, contact:

*** Autism Society of North Carolina**
505 Oberlin Road, Suite 230
Raleigh, NC 27605-1345
Tel. (919) 743-0204
web: www.autismsociety-nc.org

✽ Institute on Disabilities/UAP
Temple University
Room 423 Ritter Annex
1301 Cecil B. Moore Ave.
Philadelphia, PA 19122
Tel. (215) 204-1356 (voice/TTY)
Fax (215) 204-6336
web: www.temple.edu/inst_disabilities

Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
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